


Family overrule of registered refusal to donate organs

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Abstract

It is well known that families frequently overrule the wishes of dying patients who had previously expressed a wish to donate their organs. Various strategies have been suggested to reduce the frequency of these ‘family overrules’. However, the possibility of families overruling a patient’s registered decision not to donate has not been discussed in the medical literature, although it is legally possible in some countries. In this article, we provide an ethical analysis of family overrule of a relative’s refusal to donate, using the different jurisdictions of the UK, Switzerland, Germany and the Netherlands to provide some context. Despite some asymmetries between overruling consent and overruling refusal, there are some cases in which donation should proceed despite a recorded refusal to do so.

Keywords

Ethics, law, deceased donation, family overrule

Introduction

In most cases of deceased donation, the dead or dying patient has not recorded a decision regarding donation on the donor register or on a donor card, and families in many jurisdictions will be asked to make a decision themselves. Even more challenging are some cases where patients had indeed registered as organ donors but their families refused to accept the decision and stopped donation going ahead. While this might seem more straightforward than where there was no evidence of consent, some families refuse to accept the decision to donate and seek to prevent donation going ahead. When this occurs, it is commonly referred to as the ‘family overrule’, ‘family override’ or ‘family veto’. Around 10% of potential donations from registered donors do not go ahead because of this type of family resistance.¹ Many strategies have been developed to reduce the incidence of the family overrule of consent to donation, and much has been written about this type of overrule.² In this paper, we examine an even more contentious topic: family overrule of a registered refusal to donate. To do so, we will adopt a structure based on a key distinction made in a recent paper by the UK Donation Ethics Committee (UKDEC),³ which was also mentioned in another previous paper on the family overrule.⁴

Recategorisation of overrules

The final publication of UKDEC before its untimely closure was a discussion paper on the role of the family in donation. One key contribution made by this paper was an important clarification about family overrules: in fact, they are not all overrules. Analysis of the recorded reasons given by families who opposed donation from registered donors revealed that around 10% of so-called overrules are in fact new evidence that a patient had changed his or her mind since registering an intention to donate;² for example, ‘Patients had stated in the past that they did not wish to be a donor’. If this evidence was more

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recent than the entry on the donor register, it would be against the donor's most recently expressed wishes to proceed with donation.

In addition, another 30% of the reasons recorded in the annual NHS donor audit were neither overrules nor new evidence, but rather concerned cases where families had genuine concerns that donation was no longer in the patient's best interests (in accordance with what their relative would have wished for in this specific circumstance). Examples in this category include 'Family felt the length of time for donation process was too long'. Here, families might be arguing that the patient did want to donate, but had no idea of the delay involved and the distress that it could cause to family members. Under such circumstances, the healthcare professionals might decide that it is no longer in the patient's best interests to proceed with donation. If the patient's loved ones are distressed by a long delay, this should be considered as part of a holistic assessment of the patient's best interests as the desire of the patient's family and friends to avoid a long delay is not decisive here; rather, it is the assessment that donation is no longer in the patient's best interests because of the effect on the family and friends that is decisive.

Finally, UKDEC concluded that the remaining majority of so-called overrules of consent are indeed exactly that: vetoes of donation based on the family's values, rather than those of the patient. In the following three sections, we apply this useful reclassification to overrules of registered refusals.

New evidence of consent

When families provide new evidence of verbal consent to donation which is more recent than a registered refusal, this evidence cannot be disregarded and must be taken seriously. The weight of a registered refusal is lessened if there is more recent evidence which supersedes the earlier written evidence. Furthermore, it would be inaccurate to refer to provision of such evidence as constituting an overrule of refusal – rather, it is voiding the patient's refusal by updating the record of his or her wishes. Failure to acknowledge new evidence provided by a family would have several negative consequences. First, it would disrespect the patient not to facilitate donation and enable this wish to be fulfilled. Second, the family would be distressed at not being listened to and at having their relative's wishes overruled by healthcare staff. Third, allowing a recorded refusal to take precedence over subsequent consent will cost lives – if donation does not go ahead then many patients will die or suffer more.

The same logic applies in 'opt-out' jurisdictions such as Wales. If a person has registered a refusal to donate under the 'deemed consent' system, then that

could be superseded by more recent evidence. The Human Tissue Authority guidelines on the Welsh regime address this specific issue, stating that:

If the recorded decision was not to be an organ donor then this can be communicated to the family. If the family state that the person had changed their mind and wanted to donate their organs, they must provide the SNOD [specialist nurse for organ donation] with the evidence they believe proves the person did make a decision to be an organ donor and that this decision supersedes their recorded decision not to donate.⁵

Furthermore, although these guidelines concern Wales, the same logic applies in the rest of the UK, where recording refusal is also possible.

In Switzerland, there was no central organ donor registry until October 2018, and the only way of recording consent or refusal was to carry a donor card. If no such card was found, families were often asked whether the patient would have wanted to donate or to make the decision regarding donation themselves. Family overrule of refusal to donate via provision of new evidence is theoretically possible in Switzerland, but there are no recorded cases of this occurring (Swisstransplant, personal communication).

In the Netherlands, in practice, it is possible to overrule a consent registered on the national donor register, which is the case in approximately 10% of donation requests. However, there has never been an overrule of a registered refusal. Even if there is new verbal evidence that the donor wants to donate, the Dutch Transplant Foundation will not allow overrule of the registered refusal. Only if there were a signed consent dated more recently than the registered refusal could donation proceed.⁶

In Germany, the will or refusal to donate can be stated on a donor card or in a patient's last will. There is no national donor registry system. The person can state explicitly whether he or she wants to donate (all organs and tissues or only specific ones) or refuses to donate. Concerning the law, a donor card has the same status as a last will from this person and has to be respected. This also applies to the situation where the deceased refused donation and the family want to proceed with it.⁷

Reassessment of best interests

In some cases, information provided by the family will provide grounds for reassessing whether donation would be in the patient's best interests, even where a refusal has been registered. (As we have already observed, a similar assessment of the patient's best interests is undertaken when deciding whether to proceed with donation where consent is present, for example if the patient's loved ones are distressed by the

delay needed.) When a patient has registered a refusal, the family might nonetheless tell the healthcare team that ‘he had no idea that donation could save two lives and improve several others - if he had known that he would have wanted to donate’. If the family’s evidence in this regard seems credible, it will be necessary to reassess the patient’s best interests. This, too, is not a family overrule of refusal but provision of information that can inform healthcare professionals’ assessment of the patient’s best interests. Credible evidence would include statements regarding the patient’s general outlook on life, any voiced opinions about organ donation and whether he or she was a person who generally tried to help others whenever possible.

However, the parallel with best interests assessment in cases of recorded consent is harder to sustain where there is a recorded refusal and the family is willing to consent. When families genuinely say that donation would not be in a patient’s best interests despite recorded consent because he or she did not know what was involved, donation might not go ahead because consent does not mandate donation. Similarly, if there is more recent evidence of consent subsequent to a recorded refusal, this is sufficient for donation to proceed. But it is less obvious that a best interests assessment based on a hypothetical scenario could have sufficient weight to overrule a recorded refusal. In order for such an assessment to enable donation to proceed along with consent from the family, the evidence regarding refusal and the evidence regarding the claim that donation would be in the patient’s best interests must be evaluated.

First, the strength of the evidence regarding the registered refusal must be assessed. If a patient had written a formal statement setting out reasons for refusing donation, dated relatively recently, that would be very strong evidence against proceeding with donation. However, if the only evidence of refusal was an old donor card that was no longer carried by the person but found lying in a drawer, that would be relatively weak evidence. Second, the evidence provided by the family in support of donation being in the patient’s best interests must also be evaluated. If this simply amounted to one person claiming that ‘she was a nice person so she’d want to donate’, this would not be very strong evidence. Another scenario is offered by Wilkinson,⁸ who suggests that families might be distressed by donation not taking place, and that this distress could be grounds for overruling a recorded refusal to donate. However, it is doubtful whether this would be sufficient grounds for a decision that donation would be in the patient’s best interests. But if several different family members gave evidence about how the patient always tried to help people and had said since registering the refusal that donation was a wonderful thing, the evidence would be relatively strong. Donation should normally only

proceed where the evidence regarding refusal is relatively weak and the evidence regarding donation being in the patient’s best interests is strong.

For example, imagine that a patient had registered a refusal 20 years ago and not expressed any change of heart. However, his wife says that, although they had not discussed donation since then, it would be in his best interests to donate because he would have expressed a wish to donate had he known that it could save several people’s lives. If this was the only evidence, it seems likely the recorded refusal would have to stand. However, if several people provided evidence that the patient had expressed approval of donation in broad terms and was a charitable person who aimed to help those in need, that might be deemed sufficient grounds to conclude that donation would be in the patient’s best interests.

Genuine overrules of refusal

Finally, should families be able to ‘genuinely overrule’ a patient’s refusal to donate where there is no new evidence of consent and there are no grounds for reassessing the patient’s best interests? Overruling consent to donation is relatively easy to accomplish, while overruling refusal is regarded as extremely controversial; yet, overruling refusal can save and improve several lives, while overruling consent can lead to avoidable death and suffering amongst potential recipients.

However, it is generally believed that people have a right to control what happens to their bodies after death, and contravening their wishes and removing organs are regarded as a more serious violation than overruling a wish to donate. However, both removing organs in the face of refusal and preventing donation when the patient consents violate the right to control one’s body after death, even if the former seems intuitively worse than the latter. Concerns about bodily integrity are also at play here: if someone gives their permission for organs to be removed, this provides consent to commit an act that would otherwise be a violation of bodily integrity. In contrast, removing organs when the patient has refused to allow this violates the patient’s bodily integrity. (Wilkinson⁸ has argued that there is no posthumous right to bodily integrity, but the intuitive notion of such a right may be involved in the intuition that organs should not be taken without consent.) Any such attempt to enable donation would be based not on the patient’s wishes or interests but upon the family’s own values. Just as genuine overrule of a recorded consent to donation is morally problematic,² allowing genuine overrule of a refusal to donate is a challenging proposition – even more so given the aforementioned asymmetry regarding permission and violation of bodily integrity. Allowing such overrules could weaken trust in the

donation system and might also encourage families in attempts to overrule consent to donation.

Conclusion

The idea that a family could overrule a registered refusal to donate organs might seem counterintuitive. While we have concluded that genuine overrule of refusal to donate should not be permitted, we also hope to have shown that there are circumstances in which a recorded refusal could and should be disregarded. If convincing new evidence of consent is offered by family or friends, donation should proceed. If information provided by family or friends suggests that donation would be in the patient's best interests despite evidence of refusal, donation could proceed only if the evidence in support of this claim is strong. Overrides of registered refusal based on the wishes of the family should not be permitted, but families should be able to provide specific evidence of consent to donate and evidence in support of the claim that donation would be in the patient's best interests. On this basis, it is morally prudent to never accept a refusal to donate at face value and always discuss donation with the patient's family.

Authors' contributions

This article arose from earlier work by the ESOT ELPAT Deceased Donation Working Group on the family overrule of donation. The topic was discussed at several meetings over two years, and all authors were involved in developing the ideas. DS wrote the first draft. Several drafts were circulated, and all authors contributed content and revised the various versions.

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